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# **Patient experience after lower extremity amputation for sarcoma in England.**

## **A National Survey.**

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## **Abstract**

*Purpose:* After amputation, rehabilitation and limb fitting services are critically important to optimise outcomes. We investigated the reported patient experience and variation in limb fitting services after amputation for musculoskeletal tumours in England.

*Methods:* A postal survey instrument was developed following literature review, patient and clinician consultation and piloting. The survey was sent from each of the five bone tumour surgical centres in England.

*Results:* One hundred and five responses were received from 250 patients (42%). The number of limb fitting centres accessed by each surgical centre varied from 2 to 28. Many patients reported care falling short of national standards in areas including pre-amputation counselling, information provision, meeting someone with a similar amputation before surgery, psychological support and falls management. Patients were seen sooner where limb fitting services were on site. Many patients rely on being driven, ambulance and public transport to access services.

*Conclusion:* This study demonstrates variation in the reported experience of limb fitting services by sarcoma patients. Areas for improvement include information provision, pre-amputation counselling, psychological support, and falls management. Clinicians should be aware services are highly variable, and this may impact on outcomes. Patients treated in sarcoma centres with limb fitting services on site may experience better care.

## Introduction

In the United Kingdom, there are around 2 million people living with cancer and 500,000 people living with poor health, physical function or disability after cancer treatment [1]. Survivorship care is important and has been championed in initiatives from Macmillan, the Department of Health, and the National Cancer Intelligence Network (NCIN) [2]. Treatment for extremity sarcoma routinely involves the removal of large volumes of muscle and bone and radiotherapy, and some patients undergo amputation. Survivors therefore face problems with physical and psychological functioning, pain and reduced quality of life [3]. There are approximately 1035 new diagnoses of extremity bone or soft tissue sarcoma each year in the UK, of which around 7% will be treated with amputation [4].

The rarity and heterogeneity of sarcomas mean that treatment is centralised in specialist units to which patients may have to travel long distances and rehabilitation strategies have to be individualised. Effective support and rehabilitation are critically important if survivors of sarcoma are to maximise their potential and return to normal living. After amputation, patients often rely on non-specialist local services to deliver appropriate information, physiotherapy, occupational therapy, psychological counselling and prosthetic services, although there may be little experience of patients treated for sarcoma.

Although there are national standards relating to the care that patients should receive around amputation [5–7], our experience was that patients received rehabilitation and limb fitting services that were highly variable in terms of their quality. We were therefore interested in exploring and describing the experiences of patients and comparing them to published national standards. We also aimed to identify opportunities to share good practice with the ultimate goal of improving outcomes for these patients.

Specific objectives were to:

1. Compare the experience of limb fitting services against recognised national standards
2. Investigate national variation in limb fitting services
3. Identify areas of good practice
4. Identify areas where improvement is needed and make recommendations about them

## Methods

This was a cross-sectional survey of patients from five specialist centres for bone tumour surgery in England, all of which also treat patients with soft tissue sarcomas. Inclusion criteria were: a diagnosis of primary bone or soft tissue tumour in the lower extremity or pelvis; primary or secondary amputation (removal of major limb segment, including rotationplasty); over 8 years of age when surveyed; and at least 1 year since surgery. Adults were defined as 18 years or over at assessment, children under 18 years. Children could seek the assistance of their parent/guardian, if they preferred or needed to do so. Patients undergoing treatment for active disease were excluded.

A patient completed survey instrument was developed. This included measures of pain, physical functioning and quality of life, the results of which are reported elsewhere [8]. Questions about service provision were derived from existing standards [5–7], from a Servqual questionnaire [9] for assessing the quality of prosthetic service provision and following discussions with a small sample of service users (n=3) and staff in a limb fitting service (n=2). This survey tool was piloted in a small sample (n=3) before implementation to assess acceptability and readability. The survey tool was adjusted after the pilot, using feedback from patients and health care professionals.

The survey was distributed from the five specialist commissioned centres for the surgical treatment of primary bone tumours in England. These are: Royal Orthopaedic Hospital, Birmingham; Royal National Orthopaedic Hospital, Stanmore; Nuffield Orthopaedic Centre, Oxford; Robert Jones and Agnes Hunt Hospital, Oswestry and Newcastle Upon Tyne Hospitals NHS Foundation Trust. The study was coordinated from Newcastle, but patients were identified and sent questionnaires by their treating centre. Each patient was identified by participant number, the key being retained by their treating centre. A convenience sample of patients was identified from patients in clinics and databases at each centre by the site-coordinator. A single reminder letter was sent from the treating centre to non-responders. Data about diagnosis and level of amputation were provided by the treating centre.

This study was funded by the NHS National Specialist Commissioning Advisory Group as a Quality Improvement Development and Innovation Scheme (QIDIS) project. The project was registered as a national clinical audit and hence approval was obtained from the Clinical Risk and Effectiveness and Research and Development departments in each centre.

## **Analysis**

Descriptive statistics were calculated using means (standard deviation) for parametric and medians (range), and inter-quartile range (25<sup>th</sup> percentile - 75<sup>th</sup> percentile) for non-parametric data. Significance was taken at the 0.05 level. The Statistical Package for the Social Sciences (SPSS) software version 21 was used. The number of respondents to each item varied and is shown when reporting item scores. The Kolmogorov-Smirnov or Shapiro-Wilk test was used to test normality based on larger or smaller sample sizes respectively ( $p < 0.05$ ). Levene's test was used to assess homogeneity of variance. The Mann-Whitney U Test was used to compare continuous variables relating to patient experience between services with limb fitting centre on site versus those with no limb fitting centre on site. Pearson's Chi-square test was used to compare categorical variables and the Kruskal-Wallis Test was used to study differences in patient experience by amputation level

## **Results**

Two hundred and fifty questionnaires were sent from the five centres and following a single reminder, 105 responses were received, 101 from adults and 4 from children between September 2012 and June 2013, a response rate of 42%. The number of responses varied by centre (Table 1). The number of responses to each item is reported with each item. The one respondent from centre 5 only filled out part of the survey tool, the results from which were included where appropriate.

## Demographics of respondents

The median age of 105 respondents was 54 years (range 14-91). One hundred and one were from adults and four from children. Sixty three (of 102 respondents to the question, 62%) were male and 39 (38%) female. 68 (of 103 respondents, 66%) had a malignant bone tumour and 35 (34%) a malignant soft tissue tumour. Of patients who had bone tumours, the diagnosis was osteosarcoma in 27, chondrosarcoma in 24, Ewing's sarcoma in seven, spindle cell sarcoma in four, and one each of adamantinoma, malignant giant cell tumour, fibrosarcoma, angiosarcoma of bone, hemangiopericytoma of bone and sarcoma not otherwise specified (NOS). Of 37 patients with a soft tissue tumour the diagnosis was synovial sarcoma in seven, spindle cell sarcoma in three, angiosarcoma in five, myxofibrosarcoma in five, malignant fibrous histiocytoma in three, leiomyosarcoma in three, malignant peripheral nerve sheath tumour in two, pleomorphic sarcoma in two, and one each of fibrosarcoma, giant cell tumour of tendon sheath, liposarcoma, myxoid sarcoma, soft tissue chondrosarcoma, soft tissue Ewing's sarcoma, and soft tissue sarcoma NOS.

Of 105 respondents the amputation level was hemipelvectomy in 22 (21%), hip disarticulation in nine (9%), transfemoral in 39 (37%), knee disarticulation in two (2%), transtibial in 30 (29%), minor in two (2%) and rotationplasty in one(1%). The two patients with minor amputations were excluded from further analysis.

Amputation levels varied by centre, with two centres (centres 1 and 3) performing more proximal amputations (Table 1).

*[Insert Table 1 about here]*

## Access to services

There was variation in the use of limb fitting services by patients from each centre. Centres 2, 3 and 5 had a limb fitting centre on site, whereas centres 1 and 4 did not. The number of limb fitting



centres accessed by patients in centre 1 was 28, in centre 2 was 4, in centre 3 was 12 and in centre 4 was 2. There was only one respondent from Centre 5 (Table 1).

The time taken to be seen in limb fitting after amputation varied by centre (Figure 1). The mode response in centre 1 was between 3 and 6 months and in centres 2 and 3 was between 1 week and 1 month (Figure 1). *[Insert Figure 1 about here]*. 39/84 (46%) respondents reported driving themselves to the limb fitting centre, 29 (35%) driven by someone else in a private car, 12(14%) used an ambulance or ambulance car and 4 (5%) public transport. Therefore almost half (41/84, 49%) depended on an ambulance or on someone else to drive them to the limb fitting centre (Figure 2). Of those under 18 years of age who responded [2/3 (67%)] were driven to and one reported driving themselves to the limb fitting centre [1/3 (33%)]. *[Insert Figure 2 about here]*.

#### *Prosthesis provision and maintenance*

37/73 (51%) patients for whom an early walking aid was appropriate reported using an early walking (e.g. Femurett or Pneumatic Post-Amputation Mobility aid (PPAM)) during physiotherapy.

8/86 (9%) respondents were given a prosthetic limb for home use between one week and one month after surgery, 45 (52%) between three and six months, 15 (17%) between six and 12 months, 3 (4%) more than a year after surgery, 12 (14%) were not given a limb and 3(4%) did not remember.

Of 86 respondents, 12 (14%) were not provided with artificial limbs, 41 (48%) were provided with 1, 23 (27%) with 2, 9 (10%) with 3 and 1 (1%) provided with 4 limbs.

The 12 patients not given a prosthetic limb were of median age 68 (range 24-86) years. The proportion not given a limb varied by amputation level, being 5/22 (23%) at hemipelvectomy, 3/9 (33%) hip disarticulation, 3/39 (8%) transfemoral, and 1/30 (3%) at the transtibial level. Reasons given for not having a prosthetic limb included pain, secondary complications including infection or

tumour recurrence and one elderly patient who had a stroke. One patient reported being told they could not have a limb after hip disarticulation.

Responses to “When I have a problem with my prosthesis, the repair and maintenance of prosthesis is handled in an appropriate time?” were “strongly agree” in 27/ 74 (36%), “agree” in 22/74 (30%) “neither agree nor disagree” in 9/74 (12%), “disagree” in 10/74 (14%), and “strongly disagree” in 6/74 (8%). The proportion of patients who responded as “strongly agree” or “agree” was 21/38 (55%) from centre 1, 9/11 (82%) from centre 2, 17/23 (74%) from centre 3, and 2/2 (100%) from centre 4. (Figure 3). *[Insert Figure 3 about here]*.

Respondents were asked to respond to the statement “Athletes and military personnel perform better because they have access to better prostheses than I do”. 56/91 (62%) strongly agreed, 13 (14%) agreed, 16 (18%) neither agreed nor disagreed, 4 (4%) disagreed and 2 (2%) strongly disagreed (Box 1). Within this group, those under 18 years responded as follows: 2/5(50%) strongly agreed, 1(25%) agreed, and 1(25%) disagreed.

#### *Staff and allied health professional support*

The majority (65/86, 76%) of patients recalled being offered pre-amputation counselling. Of those who received it, 44/65 (68%) felt it prepared them well. Of those who did not receive pre-amputation counselling, 11/20 (55%) thought it would have been helpful. Similarly, only 25/94 (27%) were given the opportunity to meet someone who had already undergone a similar amputation before surgery, but most of those who had (22/24, 92%) found it useful (Figure 4).

*[Insert Figure 4 about here]*.

Falls were common, reported by 54/87 (62%) patients. However, of those who fell, most (45/52, 87%) felt that their falls were dealt with appropriately by the limb fitting centre. The rate of falling varied by

amputation level: 10/22 (50%) patients with hemipelvectomy, 2/9 (22%) hip disarticulation, 23/39 (59%) transfemoral amputation and 19/30 (63%) transtibial amputation patients reported falls

63/85 (74%) patients visited the limb fitting service for physiotherapy. Of those that did, reports suggested that care was limited.

Patients reported variable satisfaction with occupational therapy and for return to work and the work role. 10/85 (12%) were very satisfied, 8 (9%) were somewhat satisfied, 11 (13%) were neither satisfied nor dissatisfied, 4 (5%) were somewhat dissatisfied, and 6 (7%) were very dissatisfied. 46/85 (54%) reported this item was not applicable.

When asked about occupational therapy delivered training for recreational activities 16/75 (21%) were very satisfied, 14 (19%) were somewhat satisfied, 25 (33%) were neither satisfied nor dissatisfied, 9 (12%) were somewhat dissatisfied and 11 (15%) were very dissatisfied.

35/79 (44%) of patients had access to psychological support and counselling during limb fitting, but these were all patients from centres 1 and 3 (21/41 (51%) and 14/23 (61%)) respectively (Figure 5).

*[Insert Figure 5 about here].*

53/67 (79%) patients felt their complaints and feedback were dealt with appropriately; 14 (21%) patients felt that their complaints were not dealt with on time.

#### *Examples of good practice and comments for improving services*

As described in free text responses, the characteristics of good practice in centres included access, a personal approach by staff, listening and responding proactively to patient needs, and information provision (Box 2)

Suggestions for improving services included the provision of better and consistent information, in an appropriate format, such as video (Box 2).

Some patients believed that cost was a major influence on the availability of limbs. Putting a limb in for repair was a significant problem for many. Some respondents commented that their experience of private providers had been better than that in the NHS, including the availability of the C-leg

### *Geographic variation*

There was significant variation in the experience of patients treated in each centre. In general, patients treated in units with a limb fitting centre on site (n=49) appeared to have a better experience of care than others (n=56). Demographics of these groups are reported in Table 2.

#### *a. Experience of prosthetic care:*

- *Repair and maintenance of prosthesis:* Patients treated in centres with a limb fitting service on site demonstrated significantly higher levels of agreement with the statement “When I have a problem with my prosthesis, the repair and maintenance of prosthesis is handled in an appropriate time”, than those seen with in centres without a limb fitting service on site. (Mann-Whitney U Test,  $U = 494.500$ ,  $Z = -2.097$ ,  $p=0.036$ ).
- *Comfort of limb fitting:* Patients treated in centres with a limb fitting service on site demonstrated significantly higher levels of agreement with the statement “The artificial limb(s) provided is (are) comfortable”, than those who were seen in centres without a limb fitting service on site. (Mann-Whitney U Test,  $U = 641.500$ ,  $Z = -2.191$ ,  $p=0.028$ )
- *Frequency of use of limb:* Patients treated in centres with a limb fitting service on site reported a significantly higher frequency of limb use in comparison to patients treated in centres without a limb fitting service on site. (Mann Whitney U Test,  $U=607.000$ ,  $Z=-2.264$ ,  $p=0.024$ )

#### *b. Experience of physiotherapy rehabilitation:* Patients treated in centres with a limb fitting service on site reported significantly higher levels of agreement with the statement “my physiotherapist

set clear rehabilitation goals”, than patients treated elsewhere (Mann-Whitney U Test,  $U=675.000$ ,  $Z=-2.230$ ,  $p=0.026$ ).

- c. *Experience of occupational therapy provision:* Patients treated in centres with a limb fitting service on site demonstrated significantly higher levels of satisfaction with occupational therapy support for training for recreational activities, than those treated in centres without a limb fitting service on site (Mann-Whitney  $U = 386.000$ ,  $Z = -3.376$ ,  $p=0.001$ ).

Patients treated in centres with a limb fitting service on site were more likely to: receive pre-amputation consultation (31/42 (74%) vs 34/53 (64%)); meet a patient with a similar level of amputation before surgery (15/41 (37%) vs 10/53 (19%)); be seen sooner after amputation (20/39 (51%) patients treated in centres with a limb fitting service on site were seen between 1 week and 1 month post-surgery, compared with 12/36 (33%) patients in centres without a limb fitting service on site); be given a limb to use at home (3/38 (8%) patients were not given a limb in centres with a limb fitting service on site vs 9/48 (19%) in other centres ); be issued with a limb sooner (6/38 (16%) patients given a limb to use at home between 1 week and 1 month post surgery versus 2/48, (4%)).

Further exploratory analysis examined whether differences in service experience were driven by differences in amputation level between centres. No significant differences were found for experiences of repair and maintenance of prosthesis, physiotherapy, occupational therapy, or access to expert medical/nursing care (Kruskal-Wallis Test,  $p>0.05$ ). However differences in comfort of limb fitting and frequency of limb use appeared to be driven by amputation level ( $p<0.05$ ).

Patients treated in centres with onsite limb fitting services did not differ from others by age (Mann-Whitney U Test,  $U=1097.0$ ,  $Z=-0.722$ ,  $p= 0.470$ ), time since surgery (Mann-Whitney U Test,  $U= 1290.5$ ,  $Z=-0.169$ ,  $p=0.866$ ), gender (Pearson’s chi-square test  $p = 0.541$ ) and type of tumour (bone or soft tissue tumour) (Pearson’s chi square  $p=0.880$ ). However there was a higher number of proximal amputations in centres without onsite limb fitting services (Pearson’s chi square test with important

amputation level groups (hemipelvectomy, hip disarticulation, transfemoral and transtibial amputation) and no cells having an expected frequency <5,  $p=0.002^*$ ) (Table 2). *[Insert Table 2]*

When the results of the survey are compared against national standards, services fell short in providing pre-amputation counselling, meeting with an appropriate established amputee before surgery, access to psychological support and support with return to work (Table 3).

*[Insert Table 3 about here]*

## **Discussion**

This is a novel national survey which has investigated the reported experience of patients of services after amputation for sarcoma. The frequency of long term problems such as pain, psychological and physical disability in this population demands the provision of appropriate psychological support, pain and rehabilitation services if outcomes are to be optimised [3]. We have shown there is considerable variation in the experience of care and that services often fall short of declared national standards (Table 3).

Pre-amputation counselling is an important part of the rehabilitation pathway. The consultation allows the patient to understand what life after amputation and rehabilitation involves and supports informed decision making about care, particularly if amputation is being considered as an option, rather than a necessity. We have shown that many patients did not receive pre-amputation counselling and other approaches, such as the use of a video or patient leaflets might be helpful [5].

Access to limb fitting services remains challenging: our survey shows most patients are dependent on others driving them or ambulance transport. As with other aspects of health care, there is a balance between the provision of specialist services and their proximity to the patient's home, but this can be a particular issue when patients travel long distances for specialist care.

We have clearly shown that access to psychological support is variable and represents a major gap in the service, although the demand in this population is high, with those who undergo lower limb amputation tending to report anxiety and depression [10,11]. Although psychological treatment is important and improves overall outcomes in this population [12], the availability of such support is variable, being unavailable in some centres (centres 2 and 4) and only offered to a proportion of patients in others (60% in centre 3; 51% in centre 1).

We have shown that patients who have amputation for sarcoma often fall, and therefore services should be able to deal with this appropriately, given that rehabilitation programmes are of benefit after falls [13]. It was interesting to note that falls were reported more frequently in patients with more distal amputations, perhaps reflecting greater activity levels. However, we only collected limited information about this.

Repair and maintenance of prostheses are very important, particularly if the patient is only issued with one prosthetic limb, and the British Society of Rehabilitation Medicine (BSRM)[5] recognises ready access to prosthetic repair and maintenance is important. Patients may be unable to pursue normal activities while a limb is in the workshop. Our survey suggests that this could be improved, with only a proportion (49 of 74, 66%) reporting that when they had a problem with their prosthesis, repair and maintenance were handled in an appropriate time.

The number of limb fitting services used by each centre reflects the referral patterns of each as patients travel long distances for specialist sarcoma care. It is undoubtedly difficult to establish and maintain standards of specialist care across a large number of services but mechanisms for this would be helpful. Having a limb fitting service on site for sarcoma patients appears to be advantageous, with patients experiencing better services, including pre-amputation counselling, being seen sooner after surgery, and being issued with a limb for home use sooner. The concentration of expertise and facilities for patients who have had amputation after trauma, particularly of military patients has been seen as

advantageous. Given the differences between our patients and the majority of patients who have amputation, there is an argument for reducing the number of limb fitting service providers for sarcoma amputees in order to develop expertise, as for military amputees [14]. However, there is clearly a tension with the ability of patients to travel for limb fitting and the convenience of a more local service. Solutions for delivering highly specialised rehabilitation care close to home are therefore required.

This is a unique study which has attempted to describe the patient experience of limb fitting and rehabilitation after amputation for sarcoma at a national level. A major strength is the use of an evidence based survey instrument designed following literature reviews, and patient and clinician consultation as well as the use of the Servqual questionnaire, which allowed us to capture the varying service provision in this population.

It is recognised that the response rate is relatively low (42%) and there is therefore a risk of response bias, but nevertheless the cohort is the largest described in England, and the sample size seemed reasonable given the aim of the study. Furthermore, the number of responses from each centre varied widely, likely reflecting the size of each centre. For example: 53/105 responses were from one of the largest centres, and only 3/105 (2 and 1) were from smaller centres (centre 4 and 5) (Table 1). Given the small number of respondents in centre 4 (n=3) and centre 5 (n=1), descriptive statistics only were used to explore patient experiences in all five centres. However, there were statistically significant differences between units with a limb fitting service on site (n=49) compared to those without (n=56). There was further variation in the range of “time since surgery” (2 – 749 months), and “mean time since surgery” between centres (Table 1), which we recognise are potential sources of bias. We attempted to send reminders, but the study was structured such that centres were asked to communicate directly with patients in order to maintain central anonymity of the data. This meant that only one reminder was sent. Furthermore, some patients had been treated for sarcoma several years ago, meaning there is a risk of recall bias, even though “I do not remember or cannot remember”



was included as an option. However, questions about ongoing treatment are likely to remain relevant. Future studies could involve the use of a validated instrument to roll out into clinical practice.

This work has built on a previous systematic review which showed that disability and impaired physical functioning are major issues for survivors of extremity sarcoma and which therefore demand high quality rehabilitation services [3]. This study has given us a detailed insight into a complex and varied subgroup of patients who have had amputation for extremity sarcoma and has shown that services across England are highly variable and fall short of recognised national standards. This may have an impact on disability, dependency and employment. In patients treated with amputation for sarcoma, physical functioning is associated with quality of life [8] and therefore poor quality rehabilitation services are likely to have significant impact on other aspects of life and the burden on society. We have therefore shown that there is an urgent need to improve service provision to patients diagnosed with sarcoma who have undergone or are facing amputation. This needs to be improved through the delivery of improved assessments and treatments which have an impact on survivorship outcomes. Areas in particular need of improvement include occupational therapy and psychological support. Remotely supporting patients using telehealth interventions may be a helpful and cost effective approach [15].

We have suggested recommendations for improvement which include development of services with a special interest to raise the overall standard and disseminate good practice, encouraging good communication between treating centres and limb fitting services, provision of better information to patients, and improving the experience of patients to help pre-operative understanding. An excellent example of the direct translation of recommendations into clinical practice is that one of the participating centres has subsequently set up a dedicated amputation clinic, to ensure patients are provided with specialized care. In another centre, the rehabilitation team has started contacting local physiotherapists to ensure appropriate follow-up of patients and delivery of specialized care in locally. Ongoing audit of the patient experience will be important to inform commissioning of

services which should include psychological support, pain services and should consider access including transport.

## **Conclusion**

There is a wide variation in the experience of limb fitting services following amputation for sarcoma. Variations in service provision include access to psychological support, use of pre-amputation consultation, access to services, including early walking aids and prosthetic repair. Addressing variation in care through developing services and solutions for delivering expert care close to home are needed.

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## **Declaration of Interest**

The authors report no declaration of interest.

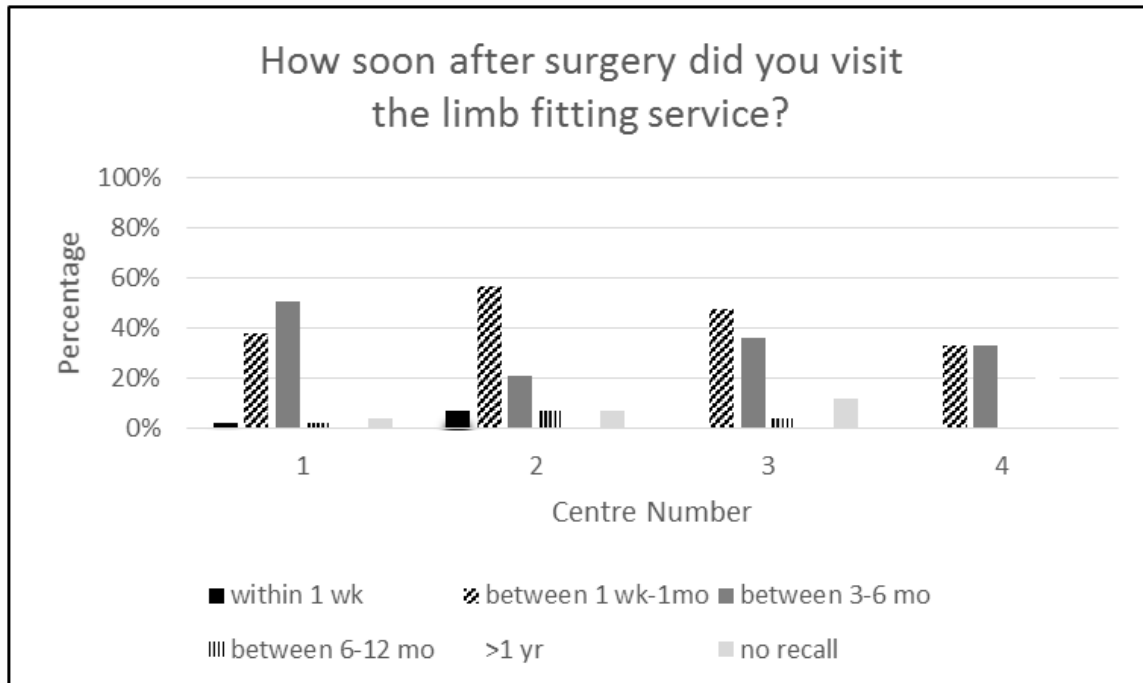
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**Caption for figures:**

*Figure 1: Time taken to be seen in the limb fitting service after amputation.*



*Figure 2: Mode of transport to the limb fitting service.*

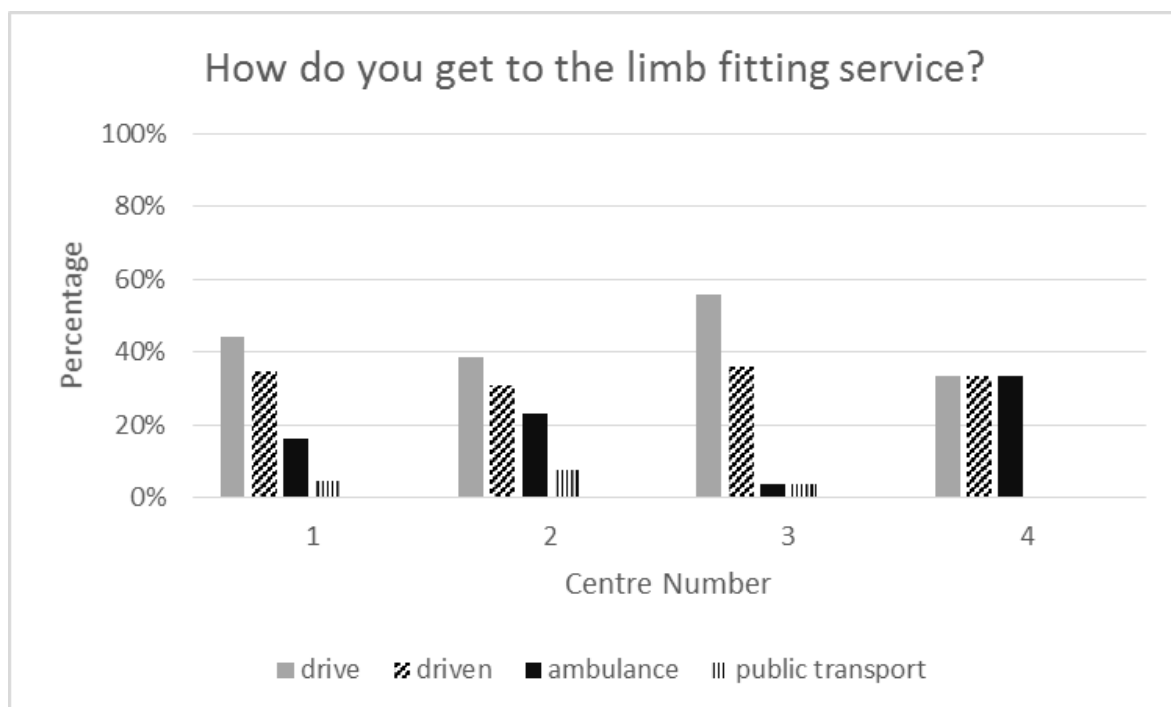


Figure 3: Meeting someone with a similar amputation before surgery.

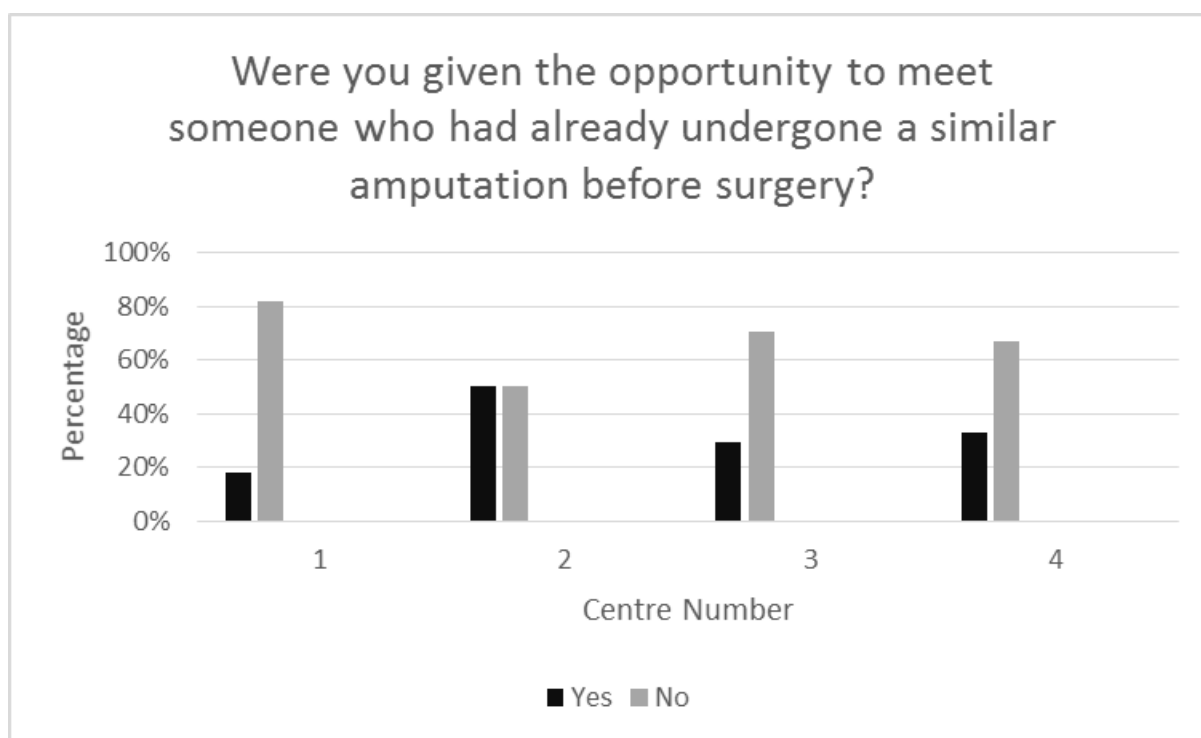


Figure 4: Repair and maintenance of prosthesis

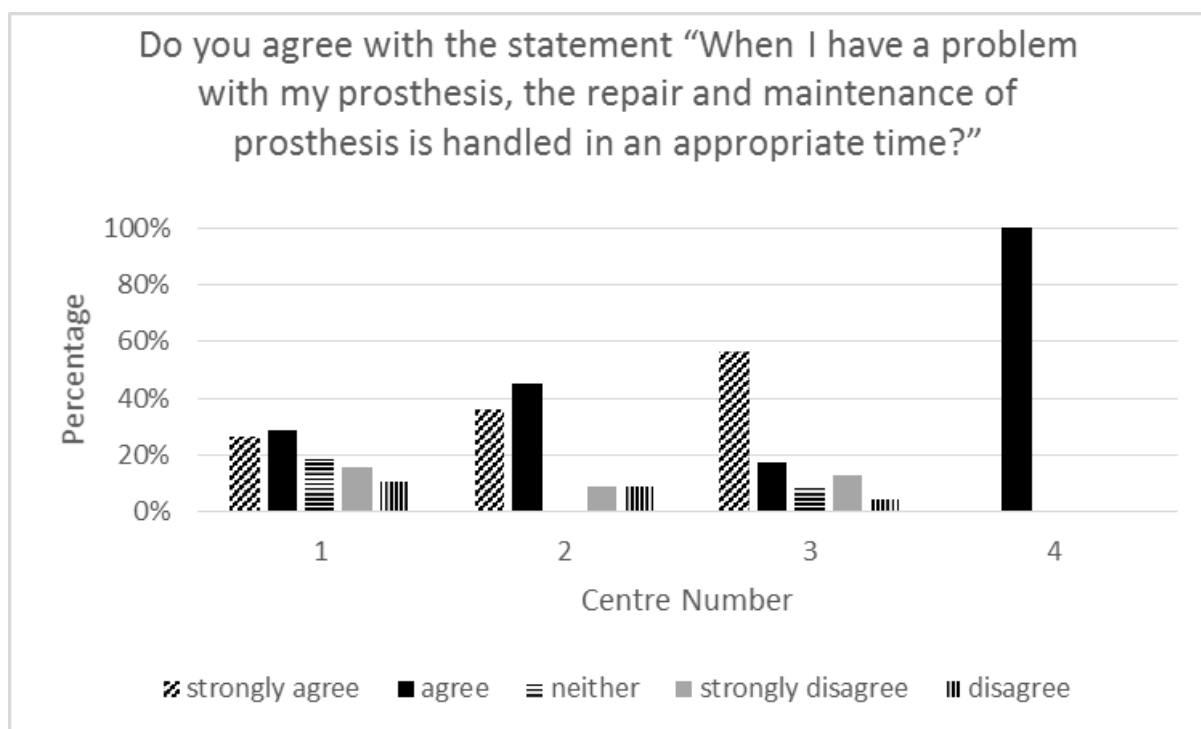
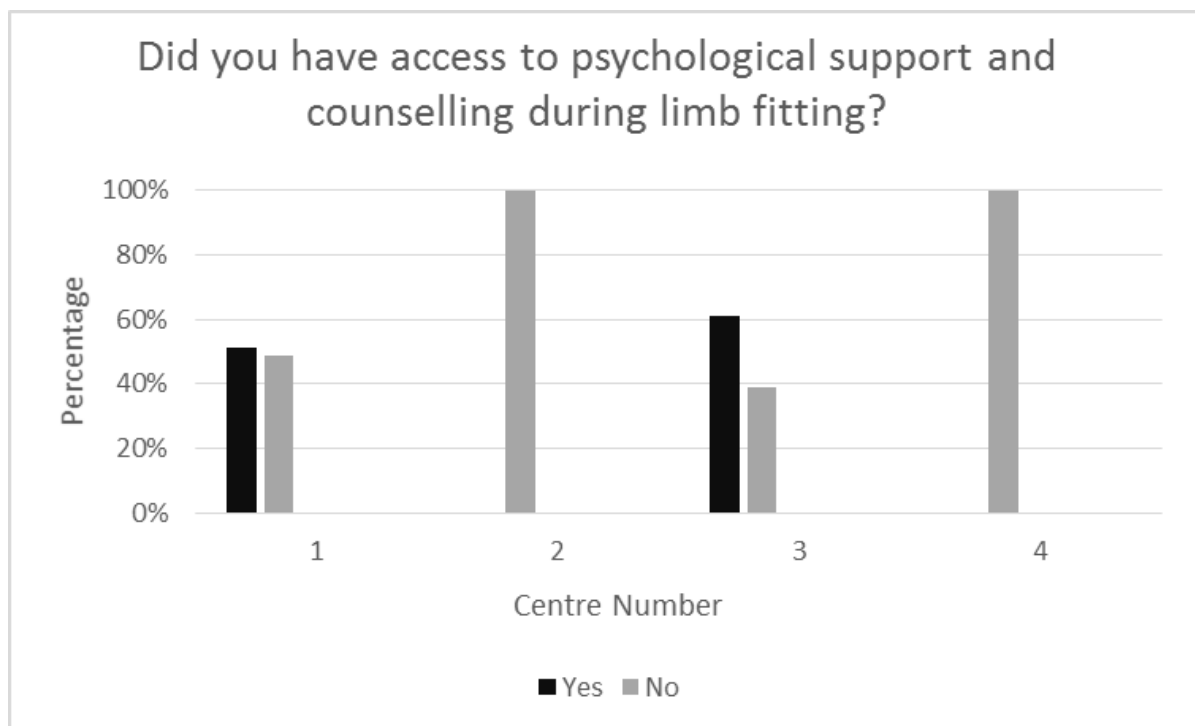


Figure 3: Psychological support and Counselling during limb fitting.



**Tables:**

**Table 1. Demographics and number of limb fitting services used**

		Centre 1	Centre 2	Centre 3	Centre 4	Centre 5
Total number of respondents		53	21	27	3	1
Mean age +/- Standard deviation (S.D) (minimum-maximum, range)		51.5 +/- 21.2 (17-84, 67)	45.6 +/- 23.7 (14-89)	52.6 +/- 17.1 (23-86)	79.3 +/- 12.0 (67-91)	82
Level of amputation  (% of total from each centre shown)	Hemipelvectomy	18(34%)		4(15%)		
	Hip disarticulation	5(9%)		3(11%)		1(100%)
	Transfemoral	21(40%)	11(52%)	6(22%)	1(33%)	
	Knee disarticulation		1(5%)		1(33%)	
	Transtibial	9(17%)	6(29%)	14(52%)	1(33%)	
	Minor Amputation		2(9%)			
	Others (Rotationplasty)		1(5%)			
Mean months after surgery +/- Standard deviation (S.D) (minimum-maximum, range)		62.4 +/- 33.9 (2-123, 121)	85.9 +/- 55.5 (13-194)	53.1 +/- 31.9 (21-124)	283.3 +/- 403.5 (36-749)	32
Number of limb fitting services used		28	4	12	2	N/A



**Table 2: Comparison of demographics between centres with limb fitting service on site versus services with no limb fitting service on site:**

Demographics	Sub-categories	Centre with limb fitting service on site	Centre with no limb fitting service on site	Statistical test  P value for difference between levels (* = statistically significant)
<b>Age (Median (range), Inter-quartile range (25<sup>th</sup> percentile - 75<sup>th</sup> percentile)</b>		50 (14-89), 32 (34 – 65)	61 (17-91), 41 (29 – 70)	p=0.398.
<b>Time post surgery(Median (range), Inter-quartile range (25<sup>th</sup> percentile - 75<sup>th</sup> percentile)</b>		49 (13-194), 70 (32.5 – 102)	63.50 (2-749), 63 (33-95.8)	p=0.910
<b>Gender</b>	<i>Male (M)</i>	31/48 (64.6%)	32/54 (59.3%)	p=0.581
	<i>Female (F)</i>	17/48 (35.4%)	22/54 (40.7%)	
<b>Type of tumour</b>	<i>Bone tumour (BT)</i>	32/49 (65.3%)	36/54 (66.7%)	p=0.884
	<i>Soft tissue tumour(STS)</i>	17/49 (34.7%)	18/54 (33.3%)	
<b>Amputation Level</b>	<i>Hemipelvectomy</i>	4/49 (8.2%)	18/56 (32.1%)	p=0.002* (Pearson's chi square test with important amputation level groups with 0 cells having expected frequency<5 , p=0.002* included hemipelvectomy, transfemoral and transtibial amputation groups)
	<i>Hip disarticulation</i>	4/49 (8.2%)	5/56 (8.9%)	
	<i>Transfemoral amputation</i>	17/49 (34.7%)	22/56 (39.3%)	
	<i>Through knee</i>	1/49 (2.0%)	1/56 (1.8%)	
	<i>Transtibial</i>	20/49 (40.8%)	10/56 (17.9%)	
	<i>Minor amputation</i>	2/49 (4.1%)	0/56 (0.0%)	
	<i>Other(Rotationplasty)</i>	1/49 (2.0%)	0/56 (0.0%)	

**Table 3: Comparison against national standards.**

	<b>Recommended National Standard</b>	<b>Type of Standard</b>	<b>Results of audit</b>
1.	A pre-amputation consultation with an appropriate PARC member should be arranged where amputation is a treatment option (as opposed to treatment necessity)	British Society of Rehabilitation Medicine (BSRM) – [5] Type B : Good practice	65/86, 76% of patients
2.	A meeting with an appropriate established amputee should be considered before every case of elective amputation	BSRM – [5] Type C : Desirable practice	25/94, 27% of patients
3.	Each PARC must have an established complaints procedure.	BSRM – [5] Type A: Essential Practice	53/67 (79%) patients felt their complaints and feedback were dealt with appropriately; 14 (21%) that their complaints were not dealt with on time.
4.	Rehabilitation programmes should include education on preventing falls and coping strategies should a fall occur.	Evidence Based Clinical Guidelines for the Physiotherapy Management of Adults with Lower Limb Protheses. British Association of Chartered Physiotherapists in Amputee Rehabilitation (BACPAR) guidelines [6]	Of patients who fell, most (45/52, 87%) felt that their falls were dealt with appropriately by the limb fitting service
5.	Service users within any district should have access to all appropriate rehabilitation services which aim to maximise physical, psychological and social well being	BSRM – [5] Type B : Good practice	35/79 (44%) of patients had access to psychological support and counselling during limb fitting, but these were all patients from centres 1 and 3 (21/41 (51%) and 14/23 (61%)) respectively. No patients from Centre 1 and 4 had access to psychological counselling.

6.	Support should be provided from the multidisciplinary team regarding successful work reintegration and maintenance of the work role.	Occupational therapy with people who have had lower limb amputations – Evidence Based Guidelines, College of Occupational Therapists [7].	10/85 (12%) were very satisfied, 8 (9%) were somewhat satisfied, 11 (13%) were neither satisfied nor dissatisfied, 4 (5%) were somewhat dissatisfied, and 6 (7%) were very dissatisfied. 46/85 (54%) reported this item was not applicable.
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## Box 1: Free text comments

### A. Free text comments about staff and allied health professional support:

- *"Very short term goals"*
- *"Once a week physio inadequate"<sup>3</sup>*
- *"Best for six weeks then nothing"*
- *"I thought I was rushed".*
- *"Physiotherapy was good but I felt more needed to be done, especially with going from walking with an aid to walking without an aid. I became attached to the walking stick and was scared to go outside without it - even though I could walk and didn't like the image of me with a walking stick given my age (17 years) "*
- *"Since finishing treatment and surgery there has been no psychological support or community welfare support or support finding work."*
- *"I'm convinced that cost and age rather than need is applied. Over the years I've used an artificial leg. I've broken the foot on many occasions - Not fit for purpose? Only recently been given an "upgrade". Appointments take ages ever for minor repairs. Actually repairs sometimes takes weeks."*

### B. Free text responses to the question ***Do you agree with the statement "Athletes and military personnel perform better because they have access to better prostheses than I do":***

- *"I strongly support that the military should have access to these prostheses, however anybody who loses a limb through whatever reason should also have access and the right to be as normal and pain free as possible."*
- *"With my level of amputation there is only one level of fitting limb, but I think athletes probably have more than one limb to use for different environments/jobs/sports. "*
- *"As to athletes and military personnel having better performances due to better prostheses. This I would assume to be because of different types of funding available"*

Box 2: Free text comments about good practice and from parents:

**A. Free text comments giving examples of good practice:**

- *"I can see them whenever I need to and they take the time and care to fully listen to me. They also show me information useful to me , such on driving, without me having to request it "*
- *"I was allowed time to express my views and was actively involved in my care"*
- *"I think the people make it easier than the equipment /physical part of the service itself"*

**B. Free text comments including recommendations about promoting good practice:**

- *"It would be great to have a DVD featuring amputees talking about their experiences. Also, some visual images of what a hind quarter amputation looks like!"*
- *"I was told I would have to have an amputation over the phone, when I was alone at home. Prior to surgery I was led to believe I would be able to have an artificial limb once I had healed in spite of not having "a stump", and was shown the type of prosthesis that would be suitable for me. Unfortunately after operation this was not thought to be practicable, so was never tried"*
- *"What fitters don't seem to understand is that socket comfort is the only thing that needs to be right. If the socket is comfortable, doesn't rub etc, then you could put a broom handle underneath and it would be fine. The other thing is that it is impossible to tell if a socket is suitable in those fitting rooms"*
- *"I have developed a kind of phobia towards my limb, almost like a hatred of it because it is so heavy and uncomfortable. I wish there was another way of attaching it to my body, instead of around the waist. I really miss my leg and I would love to look normal again. I would love if an engineer or someone could invent a way of attaching prosthesis instead of wearing around the waist. Then I think I would persevere with it a bit more."*

**C. Free text comments from family members/guardians of children with amputations:**

- *"Care needs to be consistent. You can't tell a child they can have a change of limb then move the goal posts without discussion. Patients need input with regards to their prosthetic prescriptions (which) would be helpful to give them better control of their life."*
- *"The only problem... had with his prosthesis was the lanyard occasionally snapped. We fully understand the reasons behind the decision. ... enjoys his sporting activity and this motivates him. He asks if any limbs or limbs are available for these activities (football/running etc)"*

**Appendix 1:**

# **Amputation for Bone or Soft tissue Sarcoma**

## **Questionnaire: Part Two**

**The Newcastle upon Tyne Hospitals NHS Foundation Trust, Newcastle Upon Tyne.**

**Oxford University Hospitals NHS Trust, Oxford.**

**The Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust, Oswestry.**

**The Royal National Orthopaedic Hospital NHS Foundation Trust, Stanmore.**

**The Royal Orthopaedic Hospital NHS Foundation Trust, Birmingham.**

Dear Patient

We would like to know more about the experience of patients who have had an amputation for sarcoma, because we are interested in whether or not the services that patients receive meet their needs. This questionnaire asks you about your experience of amputation and the limb fitting services you have received. Thank you for taking the time to complete it.

**Thank you for completing this questionnaire.**

## Section 1: Before limb fitting

*Please tick the most appropriate response:*

1. Were you offered a preamputation consultation?

- ☐ Yes
- ☐ No
- ☐ Can't remember

If you answered **yes**, how well did it prepare you for amputation?

- ☐ Very well
- ☐ Well
- ☐ Neither well nor poorly
- ☐ Poorly
- ☐ Very poorly

If you answered **no**, do you think it would have been helpful?

- ☐ Yes
- ☐ No

2. Were you given the opportunity to meet someone who had already undergone a similar amputation before the amputation surgery?

- ☐ Yes
- ☐ No

If **yes**, was this helpful?

- ☐ Yes
- ☐ No

## Section 2: Information

3. What aspects of limb fitting were you given information about? (Tick all answers that apply)

- ☐ Use of liners, socks, pads, sockets.
- ☐ Care of wound and artificial limb.
- ☐ Health promotion.
- ☐ Prevention and management of complications.
- ☐ Falls prevention and management techniques.
- ☐ Phantom limb sensation/pain.
- ☐ Limb volume changes.
- ☐ Increased effort during walking after amputation.
- ☐ Self management of artificial limb in different environments.
- ☐ Sporting & leisure activities.
- ☐ Availability of specialised local driving assessments
- ☐ Employment/Training.
- ☐ Local, national support groups and organisations.
- ☐ Support from Charities.
- ☐ Who to contact if you have a problem with your limb
- ☐ Something else (please specify) -  
\_\_\_\_\_
- ☐ Can't remember

4. Was there any other information you would have found helpful?

- ☐ Yes
- ☐ No

If you answered yes, please expand,

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### Section 3. Your experience of limb fitting

5. Which limb fitting centre do you go to?

6. How do you usually get there?

- ☐ I drive
- ☐ I get driven by someone else in a private car
- ☐ Ambulance or ambulance car
- ☐ Public transport
- ☐ Taxi
- ☐ Something else

How long (approximately) does it take you to get there?

\_\_\_\_\_ minutes

7. How soon after surgery did you visit the limb fitting centre?

- ☐ Within the first week
- ☐ Between 1 week and 1 month
- ☐ Between 3 and 6 months.
- ☐ Between 6 and 12 months.
- ☐ More than a year after surgery.
- ☐ I don't remember.

8. Did you use an early walking aid like a femurette or Pneumatic Post-Amputation Mobility aid (PPAM) during physiotherapy?

- ☐ Yes.
- ☐ No.
- ☐ Not Applicable.

If you answered yes: How soon after the surgery did you use it?

- ☐ Within the first week
- ☐ Between 1 week and 1 month
- ☐ Between 3 and 6 months.
- ☐ Between 6 and 12 months.
- ☐ More than a year after surgery.
- ☐ I don't remember.

9. How soon after surgery were you given a limb to use at home?

- ☐ Within the first week
- ☐ Between 1 week and 1 month
- ☐ Between 3 and 6 months.
- ☐ Between 6 and 12 months.
- ☐ More than a year after surgery.
- ☐ I don't remember.
- ☐ I haven't been given a limb.

10. How often do you use your artificial limb?

- ☐ Almost all the time
- ☐ At least daily
- ☐ At least once a week
- ☐ At least once a month
- ☐ Rarely
- ☐ Never

11. How many artificial limbs do you presently own?

---

12. Do you agree with the statement "When I have a problem with my prosthesis, the repair and maintenance of prosthesis is handled in an appropriate time?"

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

## This section has pairs of questions.

*Please circle the most appropriate response:*

The **first question** of each pair asks about what you think a good limb fitting service *should* be like, not about the service where you were treated.

Let's look at an example.

	Not important <span style="float: right;">→ Important</span>						
1. The artificial limb(s) provided should be comfortable.	1	2	3	4	5	6	7

Question 1 looks at the importance of the comfort of the artificial limb. If it is **very important** to you that the limb is comfortable, you should circle the number **6 or 7**. If you **don't think it is important**, you should circle the **1 or 2**. If you have less strong opinions, you can circle 4 or 5.



The **second question** of each pair looks at what you think of the limb fitting service where you were treated

Again, let's look at an example:

	Disagree <span style="float: right;">→ Agree strongly</span>						
1. The artificial limb(s) provided are comfortable.	1	2	3	4	5	6	7

Here, if you strongly agree that your limb(s) are generally comfortable, you would put a 6 or 7. If you strongly disagree, you would put a 1 or 2. If you are not sure, or do not strongly disagree or agree, use 3, 4 or 5.



13. The artificial limb(s) provided should be comfortable.

Not important —————> Important

1	2	3	4	5	6	7
---	---	---	---	---	---	---

13. *The artificial limb(s) provided is (are) comfortable.*

Disagree —————> Agree strongly

1	2	3	4	5	6	7
---	---	---	---	---	---	---

14. The cosmetic appearance of artificial limbs should be satisfactory to the patient.

Not important —————> Important

1	2	3	4	5	6	7
---	---	---	---	---	---	---

14. *The cosmetic appearance of my artificial limb(s) is satisfactory to me*

Disagree —————> Agree strongly

1	2	3	4	5	6	7
---	---	---	---	---	---	---

15. The materials and components used to make the prosthesis should be of a high quality.

Not important —————> Important

1	2	3	4	5	6	7
---	---	---	---	---	---	---

15. *Materials and components used to make my prosthesis are of a high quality.*

Disagree —————> Agree strongly

1	2	3	4	5	6	7
---	---	---	---	---	---	---

16. *Clinical staff should listen to my views on my care.*

Not important —————> Important

1	2	3	4	5	6	7
---	---	---	---	---	---	---

16. *Clinical staff do listen to my views on my care.*

Disagree —————> Agree strongly

1	2	3	4	5	6	7
---	---	---	---	---	---	---

17. *Limb fitting services should be flexible and convenient for patients*

Not important —————> Important

1	2	3	4	5	6	7
---	---	---	---	---	---	---

17. *My Limb Fitting Service is flexible and convenient for me*

Disagree —————> Agree strongly

1	2	3	4	5	6	7
---	---	---	---	---	---	---

18. Prosthetists (limb fitters) should understand the specific needs of their patients.

Not important —————> Important

1	2	3	4	5	6	7
---	---	---	---	---	---	---

18. *My prosthetist (limb fitter) understands my specific needs*

Disagree —————> Agree strongly

1	2	3	4	5	6	7
---	---	---	---	---	---	---

19. Patients should have sufficient one-to-one time with their prosthetist (limb fitter).

Not important —————> Important

1	2	3	4	5	6	7
---	---	---	---	---	---	---

19. *I have sufficient one-to-one time with my prosthetist (limb fitter).*

Disagree —————> Agree strongly

1	2	3	4	5	6	7
---	---	---	---	---	---	---

20. Patients should be provided with adequate privacy during limb fittings

Not important —————> Important

1	2	3	4	5	6	7
---	---	---	---	---	---	---

20. *I am provided with adequate privacy during my limb fittings*

Disagree —————> Agree strongly

1	2	3	4	5	6	7
---	---	---	---	---	---	---

21. New artificial limbs and repairs should be completed in a timescale that suits the patient

Not important —————> Important

1	2	3	4	5	6	7
---	---	---	---	---	---	---


21. *My new artificial limbs and repairs are completed in a timescale that suits me*

Disagree —————> Agree strongly

1	2	3	4	5	6	7
---	---	---	---	---	---	---




22. Patients should have easy access to expert medical/nursing care related to their amputation/condition.

Not important            Important

1	2	3	4	5	6	7
---	---	---	---	---	---	---

22. *I have easy access to expert medical /nursing care related to my amputation/condition.*

Disagree            Agree strongly

1	2	3	4	5	6	7
---	---	---	---	---	---	---

## Section 4.

*Please tick the most appropriate response:*

23 Where did you go for physiotherapy after surgery?

- ☐ The limb fitting centre
- ☐ Someone visited me at home

Somewhere else (please say where) \_\_\_\_\_

24. Do you agree with the statement “My physiotherapist set clear rehabilitation goals”

- ☐ Strongly agree.
- ☐ Agree.
- ☐ Neither agree nor disagree.
- ☐ Disagree
- ☐ Strongly disagree

If not, why not? \_\_\_\_\_

25. “Did you have a fall during your rehabilitation?”

- ☐ Yes
- ☐ No

If you had a fall, was it dealt with adequately?

- ☐ Yes
- ☐ No

If it was not, could you tell us why not?

\_\_\_\_\_

26. How satisfied were you with the support provided by the occupational therapist for the following:

Training for return to paid or unpaid work and maintenance of the work role.

- ☐ Very satisfied.
- ☐ Somewhat satisfied.
- ☐ Neither.
- ☐ Somewhat dissatisfied
- ☐ Very dissatisfied
- ☐ Not Applicable

Training for recreational activities.

- ☐ Very satisfied.
- ☐ Somewhat satisfied.
- ☐ Neither.
- ☐ Somewhat dissatisfied
- ☐ Very dissatisfied

27. Did you have access to psychological support and counselling during limb fitting?

- ☐ Yes
- ☐ No

28. If you had complaints or feedback were these handled appropriately by the limb fitting team?

- ☐ Yes
- ☐ No

If no, please provide more information

## Section 5. Amputation in the media

Please tell us what you think about people with amputation you see on the television or in the media.

29. Do you agree with the statement "Athletes and military personnel perform better because they have access to better prostheses than I do"

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Disagree
- ☐ Strongly disagree

**Section 6. Please answer the following questions about yourself:**

Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_ or Age: \_\_\_\_

Day/ Month/ Year

Gender:

☐ Male

☐ Female

Height in feet/inches: \_\_\_\_ Weight in pounds/stones: \_\_\_\_

Walking aid used:

☐ Yes

☐ No

Date Questionnaire Completed: \_\_\_\_/\_\_\_\_/\_\_\_\_

Day/Month/Year

**Please add any additional comments.**

***Please take a couple of minutes to check that you have answered every question. Thank you for participating in this survey***

